Palliative Patient Safety

A segurança do utente paliativo

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Keywords
Patient safety; End-of-life; Palliative care.

Abstract

Introduction*: The palliative patient is more predisposed to the consequences of the error situations.*
Aim*: To understand patient safety in the context of palliative.*
Material and Methods*: Integrative literature review which included studies of the last eleven years, using descriptors from Medline, CINAHL Plus with Full Text, and the Portuguese Open Access Scientific Repository. We consider the research question: what is meant by patient safety in need of palliative care?*
Results*: The 11 selected articles develop aspects of user safety around symptomatic control, medication errors, the incidence of home safety, quality of care, route of administration, and palliative sedation.*
Conclusions*: Predominance of the association between safety and mention of errors in medication use. Emerges a suggestion to create an error notification system in a palliative context.*

Palavras-chave
Segurança do utente; fim de vida; cuidados paliativos.

Resumo

Introdução: O utente paliativo encontra-se mais predisposto às consequências das situações de erro.
Objetivo: Compreender a segurança do utente no contexto de cuidados paliativos.
Material e métodos: Revisão integrativa de literatura que incluiu estudos dos últimos 11 anos, com aplicação dos descritores provenientes das bases de dados Medline, CINAHL Plus with Full Text e Repositório Científico de Acesso Aberto de Portugal. Considerámos a questão de investigação: o que se entende por segurança do utente com necessidade de cuidados paliativos?
Resultados: Os 11 artigos desenvolveram o controlo sintomático, erros de medicação, a incidência da segurança em domicílio, a qualidade de cuidados, a via de administração e a sedação paliativa.
Conclusões: Predominância da associação entre a segurança e a menção a erros de uso de medicação. Emerge a sugestão da criação de um sistema de notificação do erro em contexto paliativo.

Introduction

Safety is defined as reducing the risk – likelihood of an incident – of unnecessary damage to a minimum considered acceptable, and this safety culture depends on different factors: the user characteristics, the incident, the organization, and the factors that influence a given situation.[1] Danger can be seen as "... a circumstance, agent or action with the potential to cause harm.",[1] circumstance as "... a situation or factor that may influence an event, agent or person(s)" [1] and the event as "something that happens to or implies a patient".[1]

In this area, the World Health Organization (WHO) has developed several international actions to promote patient safety, including the publication of the International Classification of Patient Safety (CISD)[1] in 2009, seeking to create a language agreement and other health promotion projects.[2,3] In patient safety, everyone is involved, and their defense should be

based on several factors, among which we highlight teamwork. That allows the management of incidents, which can be understood as a process. That process involves the assessment of communicable occurrences like a near-miss – an incident that did not reach the patient –, an incident without damage – a situation that reached the patient but did not create discernible damages –, or a damage incident, which can also be designated as an adverse-incident event that results in harm to the user.[1,4] In this field, we also address the concept of error that is, "... failure to perform a planned action according to the desired or the incorrect development of a planes".[1]

One of the main steps in Portugal was initiated by the risk management, which configured different actions: Incident notification system, risk identification and assessment, monitoring of patient safety indicators, and auditing as an instrument for continuous improvement. [4] In this aspect, the Nurses' College (EO) highlights the primary role of nurses in this safety culture, their principle of responsibility in the care, and how the same is intrinsically related to prevention culture and risk management. The Deontological Nurse's Code includes a set of articles that refer to the person protection, their rights and duties, the freedom of choice and the empowerment promotion of the other as an informed patient, being evident the ethical duties of the Nurse to the patient and the Society, considering quality of care promotion.[1,5,6]

As mentioned, it is essential to understand how previous principles embedded in a healing culture apply when we intend to respond to the palliative patient needs.[9] To approach this stage of life implies the maintenance of a safety culture adjusted to the palliative care: interdisciplinary, organized care, aimed at patients with incurable and/or chronic disease, with limited prognosis, for the relief of suffering, pain but considering, as well, the psychosocial and spiritual aspects to which support must be given.[7,8,9]

Material and Methods

An integrative literature review was carried out based on scientific documentation obtained from a database complemented by technical documentation, present in books and other publications.

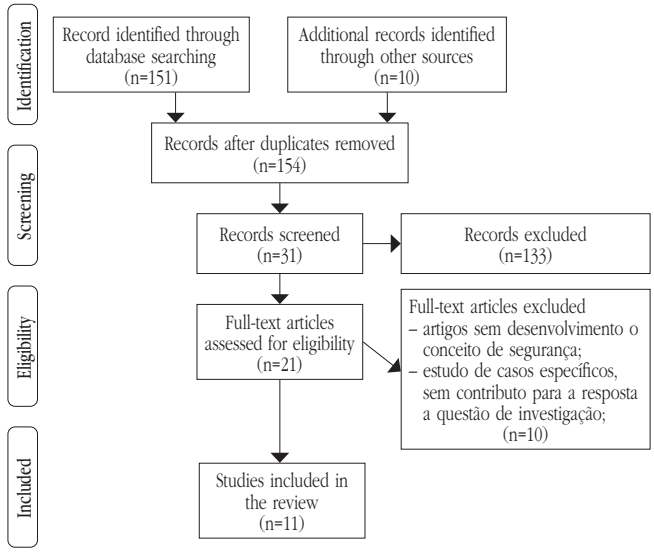
All readings were considered, and information synthesized in order to achieve the study goal, interpreting and contextualizing the results/meanings obtained. The studies selected for research use the following keywords: "patient safety", "end of life" and "palliative". Considering the shortage of publications about the subject (2006 to 2016) the articles selected were from Medline, CINAHL Plus with Full Text and the Portuguese Open Access Scientific Repository.

Between the 7th and 22nd of January, 11 articles were selected, after applying the appropriate inclusion/exclusion criteria (Figures I and II). It was considered the research question: what is meant by patient safety in need of palliative care?

Figure I – Inclusion/exclusion article criteria

Article inclusion/exclusion criteria
Participants: adults **Intervention**: patient safety concept development applied to the palliative context **Time**: 2006 – 2016 **Paradigm**: qualitative or quantitative study **Languages**: English or Portuguese

Figure II – Diagram based on PRISMA 2009[10]



Results

In patient safety, factors such as falls, delirium, pressure ulcer prevalence of medication errors could be relevant, but when applied to palliative care, the perspective changes considering the vulnerability of the palliative patient.[5]

Of the eleven articles explored: 4 addressed symptomatic control and medication error; 4 explored in a general way the theme of the safe care and, curiously, with high incidence in the home space; 1 the quality of care, aspect intrinsically related to safety; 1 focused on the route of therapy administration and, lastly 1 on palliative sedation (Figure II).

From the integrative review carried out, the articles that addressed both concepts were scarce – patient

Table I – Review of Selected Articles

Source	Article title	Authors	Periodic	Conclusions
Medline	*Opioid Use at the End of life and Survival in a Hospital at Home Unit*	Bengoechea I, Gutiérrez SG, Vrotsou K, Onaindia MJ, Lopez JM.	J Palliat Med. 2010;13(9):1079-1083	Approach to the efficacy and safety of opioid medication use in palliative patients in a community context.
Medline	*Opioids, Iatrogenic Harm and Disclosure of Medical Error*	Blinderman CD.	J Pain Symptom Manage. 2010;39(2):309-313	In a hospital context, the consequences of medication errors are explored in view of the vulnerability of end of life patients.
Medline	*The meaning of home at the end of life: A vídeo--reflexive ethography study*	Collier A, Phillips JL, Ledema R.	J Palliat Med. 2015;29(8):695-702.	The meaning of home space for the palliative patient - the preference for it as a place of death - and the reference to the proximity of that meaning to the concept of patient safety.
CINAHL Plus with Full Text	*Medical Errors and Patient Safety in Palliative Care: A Review of Current Literature*	Dietz I, Borasio GD, Schneider G, Jox RJ.	J Palliat Med. 2010;13(2):1469-1474.	Deepening of data on medical errors and the concept of patient safety in palliative care. We confirm the scarce bibliography on this subject when we approach the perspective of the palliative patient.
CINAHL Plus with Full Text	*"Please Describe from Your Point of View a Typical Case of an Error in Palliative Care": Qualitative Data from na Exploratory Cross-Sectional Survey Study among Palliative Care Professionals*	Dietz I, Plog A, Jox RJ.	J Palliat Med. 2014;17(3):331-337.	The relationship between patient safety and the occurrence of medical errors - the understanding of error in the context of palliative care. Errors that fall into areas such as: errors of interpretation / communication, system failure, dysfunctional attitudes, lack of knowledge, misuse of technology and error of judgment. The main errors are concentrated in the medication and communication area.
Medline	*The use of subcutaneous infusion in medication administration*	Gabriel J.	Br J Nurs. 2013;22(14):6-12.	The use of subcutaneous route as a means of administering therapy, indications and consequences.
Medline	*Efficacy and safety of deep, continuous palliative sedation at home: a retros-pective, single-institution study*	Porzio G, Aielli F, Verna L, Micolucci G, Aloisi P, Ficorella C.	Support Care Cancer. 2010;18:77-81.	It addresses the safety of palliative sedation, when performed in home, its application, indications, complications and consequences.
RCAAP	*A Segurança do Doente em Cuidados Paliativos: Perceção dos Profissionais de Saúde*	Ribeiro O, Cunha M, Duarte J, Ferreira AL, Ferreira AS, Venício D, et al.	Millenium. 2014;47(Jun/Dec):173-189.	Perspective of health professionals' action in the errors detection and incidents implied in the safety of the patients.
CINAHL Plus with Full Text	*Use of Opioids and Sedatives at End-of-life*	Sim SW, Ho S, Lalit Kumar RK.	Indian J Palliative Care. 2014;20:160-165	Perspective of the opioid use and sedative medication in the Asian region, considering the conservative action of this type of medication use.
CINAHL Plus with Full Text	*Patient Safety Incidents in Home Hospice Care: The Experiences of Hospice Interdisciplinary Team Members.*	Smucker DR, Regan S, Elder AC, Gerrety E.	J Palliat Med. 2014;17(5):540-544.	The factors of contribution to incident situations were explored - fall situation to inadequate symptomatic control. Perspective of the palliative care unit - where there is less technology presence, less invasive procedures and greater investment in continuity of care.
Medline	*Exploring the concept of quality care for the person who is dying*	Stefanou N, Faircloth S.	Br J Community Nurs. 2010;15(12):588-594.	The concept of quality of care for end of life patients, intrinsically related to patient safety.

safety and palliative care – with the development of different risk areas in palliative care practice. Only one study explored the national scope.

Given the above, patient safety issues present some particularities, such as those in the studies explored (Table I).[9]

Discussion

Administration of opioid medication is frequent in a palliative context seeking the symptomatic control in these patients. Its use involves risks, some of which may be prevented, yet there are

few studies on the safety of it.[11] The quantitative study of Bengoechea I et al[11] develops the space Hospital-Home Unit, exploring the effect of opioids in terminal cancer patients. It was mentioned some relevant aspects such as the use of opioid medication does not diminish their chances of survival; the chances of survival increased with the use of opioid medication in high doses, unlike those who maintained the consumption of regular doses. Its use was considered safe and observed from admission to death. The increase in survival could also be interpreted considering that admissions were mainly due to symptomatic control, rather than to the proximity of the end of life.[11]

In the Asian context, the opioid's use is still quite conservative, so Sim S et al[12] mention not only this deficit but also the same attitude towards sedative therapy. In a qualitative research context, different barriers to the prescription of opioid medication are identified: Late referral for specialists in palliative care, myths associated with opioid medication, assessment, and consideration for pain and the inaccessibility of care provided by specialized teams in palliative care. From the patient perspective: fears associated with addiction, tolerance, side effects and lack of reporting of pain. The cultural aspect is considered an influential element about physical, psychological and spiritual pain on the part of the patients. They conclude, once again, the safety of using opioid and sedative medication and report the specificity of the barriers, whose knowledge is essential for the teams to overcome these obstacles.[12]

Blinderman C presents a study of titration of opioid medication, revealing the vulnerability of patients and the importance of error prevention and consequent harm to the patient in a hospital context.[13] While in Asia we observed the prescription reserve, in the North American continent the discussion about the titrations and administered doses of opioid medication is contrary. In this article, the search for comfort through a careful titration in perfusion of this using palliative medicine specialists, who support decision making. These authors advocate the creation of protocols that facilitate the management of complex clinical cases.[13]

Porzio G et al addresses another perspective of concern about therapeutic errors administration – palliative sedation at home.[14] In the palliative context, there is an indication of sedation, in situations of out of control symptomatic with refractory symptomatology. In this quantitative study, its applicability with a Midazolam protocol addressed to 16 patients in a total of 44 patients. It was concluded as a safe possibility, involving situations of delirium and dyspnoea. However, there was a failure to respond in the first stage of the protocol in all patients with brain metastases, with no possible explanation by these investigators.[14]

Given the community context, this is the preferred reality as a place of care and place of death in Portugal, as well as at the international level. [15-17] Collier A. et al explores the meaning of home for patients and families with the reference: "safety, home and the hospital".[15]

Regarding this data, it was concluded that the sense of security was intrinsically related to the concept of home. Considering the home space, the one where the person felt safer; the house physically considered as domicile could remain safe in the case of some patients when directly related to the palliative care unit and its professionals. The home space is effectively associated with the sense of security, but not with an adequate physical space.[15]

The quality of end of life care is addressed considering this aspect as an element related to the safety culture. Stefanou N et al emphasize the importance of supporting care for end of life patients with the health professionals' awareness,[18] impact and responsibility of care, such as the Liverpool Care Pathway.[19]

Among the different examples of compromising safety incidents – falls, pressure ulcers, side effects of therapy action, among others – the most discussed was a medication error. On this, says Dietz I et al that are frequent, with high economic and moral costs.[19] From a qualitative perspective, there is little literature on the subject, justified by the new area of palliative care. The relevance of these errors centers on the vulnerability of the patients – advanced state of disease and fulfillment of a high number of medicines, possible commitment of the state of consciousness, and less capacity for decision making. It is also important to emphasize how the end of life phase of a patient assumes importance for him/her, but also his/her family, and may compromise the performance of mourning.[19]

According to Dietz I the communication errors and their essential role are added to the ones already mentioned, emerging from the study the following areas of concern: medication, sedation, end of life care, communication, the care organization, the treatment plan, and the data collection.[20] In the scope of the communication were emphasized the interpretation errors' with the patient, family,

or team. From a perspective of understanding the causes of errors, some of them are: Communication errors, system failure, dysfunctional attitudes, lack of knowledge, misuse of technology, and error of judgment.[20] Also, the error by the maintenance of futile treatments against the patient's consideration. Once more, the importance of communication in the management of this care.

As a route of primary administration in palliative care, the oral path is highlighted,[7] however, in a compromised situation, as Gabriel J mentions the subcutaneous path is preferential, advocated in this article as being safe, comfortable and allowing meet the needs of users.[3]

In an exploratory and descriptive study by Smucker DR et al,[21] the context of the hospice and the home is studied, concluding that there is a shortage of information about the patient's safety. On the contrary, we mention the consequences of falls and, once again, the ineffectiveness of symptomatic control. Contrary to other studies, a few cases of medication error or communication were verified. The incidents verified are mainly due to the home context and the interventions carried out in this area, suggesting the development of new approaches to patients and families.[21]

As to the Portuguese context, only one study addressed the same, with a focus on the patient's safety from the perspective of health professionals highlighting the prevention of error and the promotion of quality of care.[22] According to the data obtained, the professionals who were not trained in palliative care were the ones that best identified situations of errors. In the palliative care units, a smaller number of incidents were found, which allowed us to conclude that these would be safer. Prevention measures are suggested, such as hand hygiene and the application of protective equipment, as well as the dissemination of preventive measures. Also valued, the training of nurses in this field.

It is understood the importance of end of life therapy management and the fact that incidents in these patients have a different impact regarding the traditional patient. Thus, the lack of laxatives prescription when opioid administration is given may compromise the comfort of these patients, the prevention of delirium situations, the prostration due to overdose of therapy, or the occurrence of dysthanasia are impacted reflectors on the safety of the patient. All these are aspects considered in acute situations and are essential in the health-disease process of the palliative patient and his family.[5]

Conclusions

The palliative patient safety requires the defense of holistic thinking, through which the development of resources is enhanced. Including development and care investment. Identification of the patient risk-exposed, prevention of incidents, proper identification, and reporting are essential steps in the safety culture. Creating an incident recording system designed for the palliative context is relevant as well as the consideration of care preferences and end of life measures of users is highlighted.[19] These aspects will be promoters of a safe environment, being in this scope, the role of the nurse, as the defender of the patient-family binomial, promoting the relationship of the patient with his relatives and the defence of his preferences of care and measures of end of life to be applied.

Considering the proximity of the end of life, these patients are more vulnerable and therefore require coordinated and sometimes complex care, both physical and psychological.[16] The fact is that the impact of these incidents in the health-disease patients' process is enormous, given the damage that specific errors might cause. They put in question the comfort of the person, influence or hinder the choices and end of life options and limit the relationship with others, especially by cases of infection, whose control measures may cause discomfort to the patient, prolong hospitalization, among others. The patients' transference to the hospital, in the Portuguese reality, occurs due to a shortage of resources at a community level.[23] The transfer to the hospital space occurs, which sometimes results in a situation of prolonged hospitalization, without the patient being able to plan their discharge due to inexistence or slowness in social resolution.[9,23]

Risk situations can dehumanize the end of life experience and decrease the patients' intimacy with their family[16] and are highly relevant factors, considering the high number of patients with palliative needs in the Portuguese context.[23]

These study limitations are the heterogeneity of the articles, with a lack of development of the safety culture concept applied to the palliative context, the languages considered in the studies, the research deficit in this particular area, and even more data in Portuguese territory.

It is suggested the understanding of the Portuguese reality in palliative patient safety at the community and hospital context, being emergent to understand the impact of hospital admissions on the safety of

these patients, when these spaces are dimensioned for the treatment of acute situations.

References

1. Organização Mundial de Saúde. Estrutura Concetual da Classificação Internacional sobre Segurança do Doente. Relatório Técnico Final. Lisboa: Direção-Geral da Saúde; 2011 [cited 2016 Jan 29].
2. European Union Network for Patient Safety. Use of Patient Safety Culture Instruments and Recommendations. Denmark: European Society for Quality in Healthcare – Office for Quality Indicators; 2010 [cited 2016 Jan 30]. Available from: http://www.pasq.eu/DesktopModules/BlinkQuestionnaires/
3. Gabriel J. The use of subcutaneous infusion in medication administration. *British Journal of Nursing*. 2013;22(14):6-12. doi.org/10.12968/bjon.2013.22.Sup9.S6.
4. Ramos S, Trindade L. Gestão do risco: Segurança do doente em ambiente hospitalar. Tecno hospital48 [revista em linha]. 2011 Nov/Dec [cited 2016 Feb 2]; 16-20. Available from: http://repositorio.chlc.min-saude.pt/
5. Morss S. Patient Safety and End-of-life Care: Common Issues, Perspectives, and Strategies for Improving Care. Am J Hosp Palliat Care. 2016 Sep;33(8):791-6. doi: 10.1177/1049909115581847.
6. Ordem dos Enfermeiros. Segurança do doente. Ordem dos Enfermeiros. 2005;17(Julho):1-66.ISSN 1646-2629. (Sem endereço eletrónico associado; não se apresenta disponível.)
7. Barbosa A, Neto IG, editores. Manual de Cuidados Paliativos. 2.ª edição. Lisboa: Faculdade de Medicina de Lisboa; 2010. ISBN 978-972-9349-22-5.
8. Bausewein C, Daveson BA, Currow DC, Downing J, Deliens L, Radbruch L, et al. EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services – Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement. Palliative Medicine. 2015; 30(1):6-22. doi: 10.1177/0269216315589898.
9. Direcção-Geral da Saúde. Programa Nacional de Cuidados Paliativos, 2004 [cited 2016 Jan 30]. Available from: https://www.apcp.com.pt/uploads/
10. University of Oxford, Ottawa Hospital, Research Institute. PRISMA. Transparent Reporting of Systematic Reviews and Meta-Analyses [Internet]. Oxford: 2016 [cited 2016 20 Jan]. Available from: http://www.prismastatement.org/
11. Bengoechea I, Gutiérrez SG, Vrotsou K, Onaindia MJ, Lopez JM. Opioid Use at the End of life and Survival in a Hospital at Home Unit. Journal of Palliative Medicine. 2010;13(9):1079-1083. doi: 10.1089/jpm.2010.0031.
12. Sim SW, Ho S, Lalit Kumar RK. Use of Opioids and Sedatives at End-of-Life. Indian J Palliat Care. 2014;20:160-165. doi: 10.4103/0973-1075.132654.
13. Blinderman CD. Opioids, Iatrogenic Harm and Disclosure of Medical Error. Journal of Pain and Symptom Management. 2010;39(2):309-313. doi: 10.1016/j.jpainsymman.2009.11.242.
14. Porzio G, Aielli F, Verna L, Micolucci G, Aloisi P, Ficorella C. Efficacy and safety of deep, continuous palliative sedation at home: a retrospective, single-institution study. Support Care Cancer. 2010;18:77-81. doi: 10.1007/s00520-009-0632-4.
15. Collier A, Phillips JL, Ledema R. The meaning of home at the end of life: A vídeo-reflexive ethnography study. Palliative Medicine. 2015;29(8):695-702. doi: 10.1177/0269216315575677.
16. Gomes B, Higginson IJ, Calanzani N, Cohen J, Deliens L, Daveson BA, et al. Preferences for place of death if faced with advanced cancer: a population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. Ann Oncol. 2012;23:2006-15.
17. Gomes B, Sarmento VP, Ferreira P, Higginson IJ. Estudo Epidemiológico dos Locais de Morte em Portugal em 2010 e comparação com as preferências da população portuguesa. [Epidemiological study of place of death in Portugal in 2010 and comparison with the preferences of the Portuguese population]. Acta Med Port. 2013 Jul-Aug;26(4):327-334.
18. Stefanou N, Faircloth S. Exploring the concept of quality care for the person who is dying. BR J Community Nurs. 2010;15(12):588-594.
19. Dietz I, Borasio GD, Schneider G, Jox RJ. Medical Errors and Patient Safety in Palliative Care: A Review of Current Literature. Journal of Palliative Medicine. 2010;13(2):1469-1474. doi: 10.1089/jpm.2010.0228.
20. Dietz I, Plog A, Jox RJ, Schulz C. "Please Describe from Your Point of View a Typical Case of an Error in Palliative Care": Qualitative Data from na Exploratory Cross-Sectional Survey Study among Palliative Care Professionals. Journal of Palliative Medicine. 2014;17(3):331-337. doi: 10.1089/jpm.2013.0356.
21. Smucker DR, Regan S, Elder NC, Gerrety E. Patient Safety Incidents in Home Hospice Care: the Experiences of Hospice Interdisciplinary Team Members. Journal of Palliative Medicine. 2014;17(5):540-544. doi: 10.1089/jpm.2013.0111.
22. Ribeiro O, Cunha M, Duarte J, Ferreira AL, Ferreira AS, Venício D, et al. A Segurança do Doente em Cuidados Paliativos: Perceção dos Profissionais de Saúde. Millenium. 2014 Jun/Dec; 47:173-189.
23. Afonso T. A Transferência do Utente em Fim de Vida para uma Morte em Ambiente Hospitalar – uma Inevitabilidade? [Tese de Mestrado]. Lisboa: Faculdade de Medicina, Universidade de Lisboa; 2014.